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Clinician Attitudes to Prenatal Palliative Care Consultation: An Expanded Stakeholder Survey

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Introduction: The Palliative Care Team (PaCT) has been well integrated into the Fetal Health Center (FHC) at Children's Mercy Kansas City since the center's inception in 2010. The subset of neonatologists who work in the FHC were previously surveyed on their attitudes to prenatal palliative care involvement; their responses to the open-ended survey questions were studied qualitatively and published in 2021 (Tucker et al., J Perinatol. 2021). **Methods/Results:** Following continued growth and evolution of the FHC, an expanded stakeholder survey was conducted, including additional groups of clinicians involved in prenatal and early postnatal care postnatal care for patients born in the FHC. Neonatologists, maternal-fetal medicine specialists, obstetricians, cardiologists, and cardiac intensivists were surveyed. The survey itself was also expanded to include two demographic questions and an additional open-ended question to enhance analytic depth and nuance. Responses were analyzed qualitatively for key themes. **Conclusion:** The clinician stakeholders' survey responses indicate strong support for palliative care involvement prenatally in a broad range of situations, not merely for end-of-life care. These results prompt reflection on the importance of excellent palliative care in a comprehensive fetal center and its influence on a center's reputation.

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Adapting an inpatient palliative program into an integrated outpatient perinatal care model for the Fetal Center

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Background: In 2021, the UC Davis Health Fetal Care and Treatment Center (FCTC) launched a pilot program adapting its inpatient palliative care service, Supportive Therapies and Enhanced Palliative Services (STEPS), into an integrated outpatient perinatal care model. Rather than creating a separate outpatient palliative care team, FCTC developed a collaborative approach to support patients carrying fetuses with life-limiting or high-risk conditions.

Methods: Patients who may benefit from palliative care are identified by FCTC clinicians, reviewed during weekly multidisciplinary conferences, and referred to the STEPS team, which includes a physician, advanced practice provider, and social worker. The team provides ongoing, family-centered support focused on shared decision-making and care planning across the spectrum of treatment options, from comfort-focused care to full medical and surgical intervention. STEPS remains involved throughout pregnancy, delivery, neonatal care, and subsequent hospitalizations, ensuring continuity across care settings.

Conclusion: Integrating palliative care into a fetal center promotes care aligned with family values, enhances interdisciplinary collaboration, and provides critical emotional support during complex pregnancies. This hybrid model offers a scalable framework for comprehensive perinatal palliative care in emerging and resource-conscious fetal therapy centers.

[14-143]

Serious Illness Conversations in Perinatology: A novel application of an evolving framework

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Background: Complex maternal or fetal diagnoses expose families to difficult time-sensitive decisions. The serious illness conversation (SIC) tool by Ariadne Labs helps clinicians navigate end of life and complex care discussions. This has never been adopted to a perinatal context.

We sought to modify SIC for use with pregnant patients who were at increased risk of maternal morbidity and mortality or diagnosed with a fetus with a life-limiting illness.

Materials & methods: We modified SIC for perinatal contexts and set a quality improvement goal of completing SIC with at least 90% of patients at high risk for serious maternal or fetal morbidity or mortality. We provided education to providers, drafted documentation for guiding and recording SIC in the medical record, and tracked compliance. We included patients with placenta accreta spectrum, high-risk cardiovascular disease (mWHO class III or IV), or who had a fetus with life-limiting diagnoses.

Results: In 2025, we included 60 patients with 91% completion of SIC. For placenta accreta patients, 22/24 (91%) completion. For maternal cardiac disease, 5/6 patients (83%) completion. Of the 30 fetal patients, there was 100% completion.

Conclusion: Implementation of SIC to complex fetal and maternal diagnoses in pregnancy is feasible.

[14-144]

Fetal Connections: Enhancing the Transition from Prenatal Plans to Postnatal Management for Improved Neonatal Care

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The transition of prenatal plans to postnatal management is essential for ensuring optimal neonatal care, particularly for infants with complex conditions like critical congenital heart disease (CHD). Historically, delivery and admitting teams have struggled to access prenataly-developed plans due to difficulties navigating the mother's electronic health records (EHR). Time-sensitive information for perinatal management has often been overlooked during unanticipated deliveries, and planned postnatal studies for less acute patients have sometimes been missed before discharge. To address these gaps, "Fetal Connections" application was developed as an integrated tool within the EHR. Accessible through the maternal chart during office prenatal visits, this tool enables pediatric subspecialties, including neonatology, cardiology, and neurosurgery, to document and communicate prenatal plans to neonatal and labor and delivery teams. "Fetal Connections" leverages both passive and active clinical decision support. Passive features embed prenatal plans into the maternal problem list, neonatal admission notes, and labor and delivery boards. Active features trigger best practice alerts for rapid team notification in critical cases. Since its launch, over 6,000 fetal connection plans have been created in more than 3,000 pregnancies, virtually eliminating missed plans. This tool has significantly improved communication, coordination, and neonatal care outcomes.

[14-145]**“You don’t have to go through with this”: Patient and partner experiences with challenging topics during counseling for maternal-fetal surgery****Jessica Teresa Fry^{1,2,3}**¹ Ann and Robert H Lurie Childrens Hospital of Chicago Division of Neonatology² Ann and Robert H Lurie Childrens Hospital of Chicago Chicago Institute for Fetal Health³ Northwestern University Feinberg School of Medicine Department of Pediatrics**Background/Objectives:**

Patients are presented with challenging information during counseling about maternal-fetal surgery (MFS), including discussion of pregnancy termination and possible serious intraoperative complications. Though there is a growing body of literature exploring clinician approaches to sensitive counseling, less is known about the experiences of patients and their partners discussing these topics while deciding about MFS.

Methods:

This is a sub-analysis of a mixed-methods retrospective study on MFS decision-making. We recruited participants from patients and their partners counseled about twin-to-twin transfusion syndrome (TTTS) or fetal myelomeningocele (fMMC) at a U.S. fetal therapy center. Study participants completed semi-structured interviews and an online survey which measured characteristics associated with decision-making. Interview transcripts were analyzed using a phenomenological approach.

Results/Conclusions:

Of 30 study participants, 19 described counseling regarding pregnancy termination and 16 described counseling regarding intraoperative fetal complications. For both topics, participants reported variable experiences with clinician counseling. Most appreciated the importance of discussing these subjects. However, participants experienced distress when they felt topics were overemphasized or treated insensitively. Regarding intraoperative fetal complications, participants described decisions regarding possible intraoperative delivery as among the most difficult considerations in MFS. Overall, these narratives highlight an opportunity for fetal centers to carefully consider approaches to sensitive communication.

[14-146]**Exploring opportunities to better support patient decision-making for maternal-fetal surgery****Jessica Teresa Fry^{1,2,3}**¹ Ann and Robert H Lurie Childrens Hospital of Chicago Chicago Institute for Fetal Health² Northwestern University Feinberg School of Medicine Department of Pediatrics³ Ann and Robert H Lurie Childrens Hospital of Chicago Division of Neonatology**Background/Objectives:**

There is increasing literature on patient decision-making about maternal-fetal surgery (MFS). Patient decisions regarding MFS have been described as influenced and supported by the fetal health care team, yet clinician approaches to counseling are reported to vary. This study aims to examine patient and partner experiences with MFS decision-making, with a focus on opportunities to enhance clinician counseling and support.

Methods:

In this mixed-methods retrospective study on MFS decision-making, we recruited patients from a U.S. fetal therapy center who received care for either twin-to-twin transfusion syndrome (TTTS) or fetal myelomeningocele (fMMC) and their identified partners. Study participants discussed decision-making experiences in semi-structured interviews and completed surveys measuring characteristics associated with decision-making. Interview transcripts were analyzed through a phenomenological approach.

Results/Conclusions:

30 participants completed all study components. The following represent emerging themes from analysis of participant narratives: 1) Participants described decision-making for MFS as swirling, “surreal” experiences; 2) Information from the medical care team serves as both health education and emotional support; 3) Coordination of care between local clinicians and the fetal care center is varied but important. Together, these themes both illustrate the complexity of patient decision-making in MFS and point to targets for future interventions to enhance support.

[14-147]

Optimization of an Instrument for Screening Complicated Grief after Reproductive Loss

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Objective: To determine optimal wording for an instrument to screen for complicated grief after reproductive loss (Reproductive Grief Screen [RGS]). **Methods:** Participants were recruited to this cross-sectional survey using Qualtrics and social media. Survey respondents assessed three possible ways of rewording three items in the RGS. In addition to completing a permutation of the RGS, respondents ranked the wording of each of the RGS items and completed the Arousal Adjective Checklist and the Reactions to Research Participation questionnaires to assess possible negative effects of the version of the RGS they received. **Results:** 844 women who had one or more reproductive losses after January 1, 2017. Across all permutations of the RGS, women who received the third version of one item reported greater negative symptoms using the RRPQ. The third iteration of one item in the RGS is suboptimal, suggesting that the second formulation is preferred by the target population. Participants were grateful to be asked about their reproductive losses and overwhelmingly rated all items as acceptable. **Conclusion:** When combined with other data previously published by this research team that suggested preferred wording for other items, a single preferred form of the RGS is now defined.

[14-149]**Area Deprivation Index and Termination Rates for Fetal Surgery Patients****Michael Beninati**

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Objective:

Social determinants of health (SDOH) are associated with differential outcomes in access to care. Area deprivation index (ADI) is an effective metric for SDOH as it measures an area's level of socioeconomic deprivation. We hypothesize that patients from zip codes with higher ADIs were more likely to terminate.

Study design:

Retrospective chart review of fetal surgery referrals with termination data available managed at a single fetal center from 2019-2026. Primary outcome measure was termination rate. ADI is measured on a scale from 1-10, with higher numbers representing greater deprivation.

Results:

There were 153 fetal surgery patients analyzed, of which 22 terminated (14%). Lower socioeconomic status (ADI greater than 7) was experienced by 32 (21%) of these patients. No difference was seen in rates of termination by ADI.

Conclusion:

A significant portion of patients referred to our fetal surgery program are from lower socioeconomic areas. Despite our hypothesis that patients from these areas would have higher rates of termination, no difference was seen, suggesting that patients from high ADI areas have access to the only fetal surgery intervention center in the state, and that the decision to terminate does not appear to be driven solely by socioeconomic resources.